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DIFFICULTIES OF LIVING WITH AN ILLNESS NOT CONSIDERED A “DISEASE”: FOCUSING ON THE ILLNESS BEHAVIOR OF MYALGIC ENCEPHALOMYELITIS/CHRONIC FATIGUE SYNDROME PATIENTS

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Abstract

This paper focuses on the illness behavior of patients with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) to clarify difficulties in their lives through comparison with a five-stage model of illness behavior. ME/CFS is considered a typical disease with medically unexplained symptoms (MUS), which refers to a condition where symptoms suggest the presence of a physical disease whose cause cannot be found by examination. Although previous studies of ME/CFS have focused on specific events, such as diagnosis, and the psychological changes that accompany them, the chronological events experienced by patients and the transformation of the problems they face have not been adequately grasped. This paper analyzes ME/CFS patients' illness behavior through interviews and explores the difficulties patients face at each stage of illness behavior. In ME/CFS patients' narratives, their illness behavior shows complexities of going back and forth between stages, rather than progressing step by step like an acute illness. The seemingly excessive treatment behavior called “doctor shopping” is actually linked to doctors' ignorance, suspicion, and incomprehension of diseases without a biomarker, rather than the desire of the patient to dispel an “inappropriate” label of laziness and mental illness. Indeed, it would be more accurate to say that interviewees were not accepted by several hospitals. In addition, since patients are often suspected of not being really ill even after diagnosis, they cannot experience the dependent-patient role. Therefore, by becoming an “active patient” by themselves, ME/CFS patients must undertake the “independent-patient role” to secure necessary treatment and welfare services. It should be noted that these patient behaviors are not undertaken for secondary gain but are due to their having no other way to receive necessary care.

Key words: myalgic encephalomyelitis/chronic fatigue syndrome, illness behavior, independent-patient role

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1. Introduction

According to a survey by the Ministry of Health, Labour and Welfare (2011), the total numbers of patients with major diseases in Japan are as follows: “hypertensive disease” (about 9.07 million), “diabetes” (about 2.70 million), “hyperlipidemia” (about 1.89 million), “heart diseases (excluding hypertensive-type)” (about 1.61 million), “malignant neoplasm” (about 1.53 million), and “cerebrovascular disease” (about 1.24 million). Moreover, in general, numerous patients have lifestyle diseases (Ministry of Health, Labour and Welfare, 2011). Lifestyle diseases account for about 60% of deaths in Japan, and various measures have been taken since 1981 against like cancer, which has been the leading cause of death. In recent years, as mental diseases greatly surpass “the four diseases”¹⁾ in terms of the number of patients, active measures have been taken against them²⁾ (and specifically against dementia, which is expected to further increase with the aging of the population).

Thus, it can be said that for diseases that have a large number of patients and high public interest, extensive resources are dedicated to solving these problems, which are socially shared to some extent. However, in the case of diseases with fewer patients, low mortality rates, and low public interest, it is difficult to socially share the problems that need to be solved without investing the necessary resources. In particular, in the case of illnesses whose status as diseases is not necessarily established, such as medically unexplained symptoms (MUS), it becomes more difficult to recognize the problem.

The term MUS refers to a condition where “although symptoms that suggest the presence of a physical disease are present, the cause of the disease cannot be found even after adequate search” (Miyazaki 2010: 213). There are many such diseases including myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), fibromyalgia (FM), and irritable bowel syndrome (IBS). As the cause cannot be identified even through examination, MUS tends to be treated as a clinically difficult case. This is because the patient “will not be convinced by the doctor’s explanation that there is ‘no abnormality’ and will persistently seek medical examinations and treatments without admitting the possibility of involvement of psychological factors” (Okada 2013: 77). In Europe, it has been pointed out that the care seeking behavior of MUS patients have contributed to a steep rise in medical expenses, and it is thought to be a concern not only for individual patients but also for society. In Japan, effort has been made in medical research on MUS by developing processes such as elucidating its mechanism, searching for biomarkers, and objectively establishing the symptoms; in addition, clinicians who have difficulty in dealing with unidentified complaints often report

1) This refers to the four diseases, “cancer,” “stroke,” “heart diseases,” and “diabetes,” which the government included as key priorities in the medical care plans formulated by the prefectures. Mental diseases were added in 2013 to yield the “5 Diseases.”

2) There are measures such as “Dementia Measure Promotion 5-Year Plan” with an emphasis on early diagnosis and early response (2013 to 2017) (Ministry of Health, Labour and Welfare 2013).

the problems occurring at a medical practice. Hence, the study of these problems from the viewpoint of the person concerned is still in a development stage³⁾.

Therefore, in this paper, we explore the problems surrounding MUS using interviews of the persons suffered from ME/CFS. In Japan, ME/CFS is commonly known as CFS⁴⁾. CFS is a condition wherein “a person who has been living a healthy life contracts an infectious disease or the like, which triggers strong general fatigue, slight fever, headache, muscular pain, exhaustion, difficulty in thinking, and psychoneurotic symptoms, such as depression that persist over a long time more than 6 months, thus causing a significant impairment in his/her social life” (Oka 2013: 81). As the biomarkers have not yet been identified, there is no underlying treatment. Despite having many serious patients, there is no welfare service that can be used by patients who have lost their economic foundation and cannot carry on with their social life as ME/CFS has not been institutionally recognized as an “intractable disease” or “disability.” In this paper, we focus on the illness behavior of the patients suffering from ME/CFS and try to grasp the kind of problems they face chronologically and determine when they face them. By examining the transformation process of the problems accompanying the illness behavior, we would like to clarify the difficulties characteristic to individuals with ME/CFS that has not been established its status as a disease.

2. MUS and Illness Behavior

Studies on difficulties in daily lives and social problems faced by people with MUS are very few in Japan; on the contrary, many studies have been conducted abroad. Although these are mainly disease-wise case studies, several important issues common to MUS as a whole have also been pointed out. Here, we try to organize prior research along the three themes of MUS that Nettleton (2006) presents in her own empirical research namely, “living with uncertainty,” “dealing with legitimacy,” and “resistance to psychological explanations for their suffering.”

The first theme is “living with uncertainty,” which is seriously realized in people with MUS before diagnosis. In MUS, as abnormalities cannot be identified by tests, diagnosis naturally takes a longer time. The fact that diagnosis is difficult entails a state of uncertainty wherein the person will not be able to figure out what is happening to his/her body. If such a condition persists for a long time, it may lead to mental distress and dissatisfaction with medical professionals, and the person will be forced to live in a chaotic state (Nettleton 2006; Nettleton et al. 2005).

3) In Japan, studies of the problems surrounding MUS from the perspective of the person concerned are Ono (2011), focusing on “complex regional pain syndrome,” and Hosoda (2013), focusing on ME/CFS as in this paper.

4) The name CFS is misleading in implying a mere accumulation of stress and fatigue. Hence, there are movements in numerous countries to change the name of the disease, as the current name hardly conveys its severity. Many countries use the term ME, which was used before CFS in the UK. Currently, these terms are often written together as ME/CFS or CFS/ME. In this paper, I have referred it as ME/CFS in light of international trends.

The second theme is the “dealing with legitimacy,” which is a continuation of the above-mentioned “living with uncertainty.” This is because uncertainty comes largely from not being diagnosed (Nettleton 2006: 1168). A sick person becomes a “patient” only upon diagnosis; as pointed out by Parsons, a sick person is exempted from all normal duties the moment he/she becomes a patient, and instead is required to fulfil the duties of a sick person by trying to recover from the illness by following the instructions of the doctor (Parsons 1951 [1974]). In other words, because an illness is legitimized as a socially accepted deviation only when diagnosed, MUS patients who are not adequately diagnosed cannot take up the role of a sick person and are often suspected of malingering (Broom and Woodward 1996; Dumit 2006; Hadler 1996; Nettleton 2006). Hence, diagnosis is experienced as an extremely important event for the sufferers, as it allows a sense of relief (Broom and Woodward 1996; Lillrank 2003) and collective identity (Dumit 2006; Jutel 2009), and also enables them to reinterpret their past and identity (Stockl 2007).

The third theme is “resistance to psychological explanations for their suffering,” which also results from “living with uncertainty,” and stems from the “dealing with legitimacy.” Patients who live in a chaotic state without being diagnosed can easily be suspected of being mentally ill from the doctor’s perspective, but from the patient’s perspective, “legitimizing” physical symptoms as a mental condition is unreasonable. For example, according to a research on CFS patients by Deale and Wessely, two-thirds of the respondents were dissatisfied with their medical care and more than half cited as the reason, that “their symptoms were diagnosed as mental illness which was unacceptable” (Deale and Wessely 2001). Further, even in the case of systemic lupus erythematosus, as it is not uncommon to give a psychological explanation, patients must emphasize that their symptoms are not imaginary or due to mental weakness until they obtain an adequate diagnosis (Stockl 2007).

After arranging previous studies along the three themes mentioned above, there are two issues to be considered. One is that it is mainly the patients’ psychological response to their difficulties that has been discussed. Although the seriousness of the problem has been clarified by focusing on the psychological aspects of the patients, it is still difficult to find a multifaceted perspective from which to understand the problem. The other issue is the emphasis on specific events such as a definitive diagnosis or determination of mental illness. These are prominent events for MUS patients and are no less than the themes carefully picked out from the patients’ narratives. However, focusing on specific events will cause other events or the process that led to those specific events to appear as the background, making the identification of other important problems difficult.

In this paper, by focusing on the illness behavior of MUS patients, we would like to make up for the insufficient parts of prior studies. Illness behavior refers to “any activity, undertaken by a person who feels ill, to define the state of his health and to discover a suitable remedy” (Kasl and Cobb 1966: 246). In particular, Suchman’s five-stage model (1965), which divides

illness behavior into five stages based on time succession, occupies a classical position in illness behavior theory. Each stage is briefly described below. (1) The symptom experience stage is the stage when the person realizes that “something is wrong.” There are physical, cognitive, and emotional aspects to symptom experience. The initiation of the medical care process is the patient’s subjective perception and interpretation of symptoms. (2) Assumption of the sick role stage is the stage where the person recognizes the illness and determines that professional care is needed. The person tries to make the people around him/her recognize his/her condition as a disease and seeks information or advice. (3) At the medical care contact stage, the person seeks professional medical care. Here, the sick person expects a diagnosis and treatment from “scientific” resources and not from an “lay person.” (4) In the dependent-patient role stage, the sick person assigns his self-management rights to the physician and accepts and follows the treatment. Here, the sick person becomes a “patient” for the first time. (5) The recovery/rehabilitation stage is the stage wherein the person relinquishes the patient role. In the case of acute illness, the person returns to the pre-illness state. However, in the case of chronic illness or disability, this process may be prolonged, as returning to the normal role is difficult⁵⁾.

In this paper, we will explore the peculiarities of the problems faced by ME/CFS patients by looking at the gaps between the five-stage model based on acute illness and the illness behavior of them. By adopting such an approach, the problems accompanying the illness behavior from onset to the present moment, and their transformation process will become clear; moreover, understanding some of the difficulties of living with ME/CFS, an illness whose status as a disease has not necessarily been established, will become possible.

3. Methodology

3.1. Participants

Based on the above aims, interviews were conducted with ME/CFS sufferers. In this study, 8 participants were obtained by referrals from a patient association (Table 1).

3.2. Procedure

Interview were conducted via interviews between October 2013 and January 2014. Before interviewing, the participants were informed about the following aspects regarding this study: purpose, contents, method, handling of personal information, and publication of results; their consent was obtained in writing. The main question items were as follows: (1) Attributes (age, educational background, occupation, etc.), (2) Information about the disease (comorbidity,

5) As Suchman adds, these stages do not occur in all diseases and the details of their occurrence differ between individuals. Moreover, they do not always progress in one direction, as there are cases where a certain stage is repeated or when it moves between stages.

TABLE 1. Basic attributes of participants (At the time of interview)

Participant	Patient's gender	Patient's age	Relationship with the patient	Occupation at onset	Time of onset	Time taken for definitive diagnosis
A	Female	Early 40s	Self	Employee	Late 2000s	About 2 years
B	Female	Early 30s	Self	High school student	Early 2000s	About 1 year
C	Female	Early 50s	Self	Employee	Early 2000s	About 10 years
D	Female	Late 30s	Self	Employee	Late 2000s	About half a year
E	Female	Late 30s	Self	Middle school student	Late 1990s	About 15 years
F	Male	Late 30s	Self	Self-employed	Early 2010s	About one and a half years
G	Female	Early 30s	Father	Middle school student	Early 2000s	About 3 years
H	Female	Early 30s	Self	Professional student	Early 2000s	About 2 years

treatment, medical expenses, etc.), (3) Illness behavior (① Symptom experience: Onset time, subjective symptoms, other people's reactions, etc., ② Assumption of the sick role: Reason for being convinced that one is ill, ③ Contacting a medical institution: Time of consultation / definitive diagnosis and reason, doctor's attitude, other disease names assigned,

④ Dependence on the patient role: Treatment, ⑤ Recovery and rehabilitation: Presence or absence of remission experience), (4) General life (socioeconomic situation, relations with family and friends), (5) Life history: life events, and (6) Difficulties and Demands, preparing an interview guide including these questions, we conducted a semi-structured interview for about 1 to 2 hours.

With the consent of the participant, we recorded the contents of the interview on an IC recorder and in written format. The narratives of the persons concerned used in this paper are all quotes from the verbatim transcripts of the interview data. For data analyses, in addition to intensively examining the portions related to illness behavior focused on throughout the case, we analyzed the transition of illness behavior at each stage and its factors in the context of each person's narrative⁶⁾.

4. Illness Behavior of ME/CFS Patients

Now let us examine the behavior of persons suffering from ME/CFS and the associated problems at each stage of the illness behavior.

6) As Kim points out in the case of studies with specific research questions, it is difficult to faithfully adopt the grounded theory approach (GTA) (Kim 2009: 338) because semi-structured interviews are not fully compatible with GTA which aims to be completely inductive. This paper shares Kim's awareness of issue when analyzing the data, and in addition to the open and focused coding she adopted, it refers to the process coding method that focuses on the relation between time succession and action (Saldaña 2013: 96).

4.1 Symptom Experience Stage: Difficulties in Daily Life

Although the experience of symptoms may vary depending on the individual, there are many common aspects, such as fever, fatigue, loss of thinking ability, and headache. For example, when Ms. E said, “I was aware that something was wrong,” the symptom was that despite sufficient sleep time, she was unable to get up in the morning and her thinking ability declined during the day. However, Ms. E did not take this condition seriously because “Everyone has days when he/she don’t feel refreshed and hates getting up in the mornings.” Further, Ms. H, who was a professional student at that time, said that her brain stopped working suddenly, delaying the submission of her reports and causing problems in her student life. However, as Ms. H was busy every day in studying for acquiring the qualification and as she was under the impression that the problem was psychological, she did not take immediate action.

Thus, the sufferers considered the initial conditions such as being unable to wake up in the morning and diminished thinking ability as common and temporary. Thus, even if it causes trouble in daily life and affects a person’s work or academic performance, it is extremely difficult to anticipate any further seriousness at this stage.

4.2 Assumption of the Sick Role Stage: Lack of Understanding or Misunderstanding by Others

Second is the sick role assumption stage at which the main actions usually consist of consulting with an “lay person” and trying to be provisionally recognized as sick. Although Ms. A had let it be known at her workplace that her physical condition was gradually worsening, she could not gain the understanding of the people around her as it was not a supportive work environment. Even after that, Ms. A continued to be assigned excessive amounts of work and eventually was forced to resign from her office. Further, Ms. E, who was a middle-school student at the time of onset, was not able to attend school because of the severity of her symptoms. However, her homeroom teacher concluded that she had become a truant because of emotional problems.

Ms. E: Suddenly, I stopped going to school. I couldn’t go. Although I was unable to go to school, my teacher assumed that I didn’t want to attend school rather than that I couldn’t attend. My teacher thought that my refusal to go to school was due to emotional problems. To overcome it, my teacher suggested attending the school infirmary. Well, I think it was with good intentions. However, I think my teacher had the opinion that I was just refusing to attend school. So, yes, there was a gap in recognition.

Ms. E’s narrative, emphasizing that “It was not that I didn’t want to go, but that I couldn’t,” gives a glimpse of her frustration about her physical symptoms being perceived as mental

problems. Ms. E, interpreted as a truant by her homeroom teacher, was suspected of having mental problems by her parents and continued to be regarded as “a person withdrawing from the surroundings” for about ten years.

Thus, in the cases of Ms. A and Ms. E, due to being exposed to the non-understanding and misunderstandings of the surrounding people, problems such as not being able to obtain other people’s consideration, which would normally be expected in times of poor physical conditions, and inability to use the lay referral system⁷⁾ arose. It is suggested that if a condition is not provisionally recognized as an “illness” by others who are lay persons, this may aggravate the symptoms and inhibit a smooth transition between stages of illness behavior.

4.3 The Medical Care Contact Stage: Seeking Proper Diagnosis

At the stage of contact with a medical institution, the sick person tries to legitimize the illness through the authority of medical science and not from lay persons. However, as the doctors and medical facilities that can diagnose ME/CFS are limited, it is not easy to obtain a definitive diagnosis. Even after visiting a few medical institutions, if the condition goes undiagnosed, as with Ms. C and Ms. H, it is not uncommon for the people around to say, “you are lazy” or “you are sluggish.”

Ms. C: Of course, until that [diagnosis], I was often thought to be lying. I was told that I was lazy, and I felt that I wasn’t trusted.

Ms. H: They said, “You are just being lazy and sloppy.” I have heard such words even from my family. I too have wondered why I am unable to do what I have to do.

In the case of ME/CFS, where it is hard to convey the symptoms to others visually, suffering in situations where definitive diagnosis is not obtained can be misunderstood as laziness; as mentioned above. For the sick person, it is remembered as a painful experience like the symptoms, or even more than the symptoms. Further, such unfair evaluations and misunderstandings of others include such diagnoses as “emotional problems” and “mental disorder.” For example, Ms. E felt severe distress when she was told that it was “something similar to a neurosis” at a psychiatry department where she was taken by her parents, and she stopped visiting there just after her first visit. After that, in another psychiatry department Ms. E was diagnosed as “depressed,” and feeling that her condition could not be explained solely in its mental aspects, was awaiting an “appropriate diagnosis.” Thus, it can be said that people suffering from ME/CFS seek a definitive diagnosis in order to know what is happening to

7) The lay referral system refers to the mechanism of obtaining advice from non-professionals like family members or friends (Freidson 1961). At the sick role assumption stage, this lay referral system plays an important role in evaluating symptoms and considering coping strategies before going to a medical institution.

their bodies. In other words, they seek a proper explanation for their physical condition.

Further, persons suffering from ME/CFS acquire knowledge about the symptoms from various sources such as the Internet, not depending on the doctors who cannot diagnose them properly. In many cases, this may lead to a definitive diagnosis, and in fact Ms. B received it at a hospital she found from the Internet. In the case of Ms. D, although the information on the Internet also led to definitive diagnosis, it caused a conflict between medical institutions. Although Ms. D visited the hospital for six weeks immediately after the onset, as her symptoms did not improve, she searched the Internet and guessed that it might be ME/CFS. However, as soon as she reported that to her doctor, her relationship with the hospital worsened.

Ms. D: When I checked my symptoms on the Internet and talked to them about if this could be CFS, the ○○ (hospital name) did not believe the presence of CFS at all. From that point, the interaction with the hospital changed considerably. They started treating me coldly.

In the case of a common illness, it is not necessary for the sick person to investigate the disease to obtain a diagnosis. However, in the present situation, where there are only a few doctors who can diagnose ME/CFS, the experience of the sick person trumps the doctors' knowledge.

Sick person rely on his/her experience and intuition to use various information to reach a definitive diagnosis, but ME/CFS, whose status as a disease has not been established, once sick person has spoken its name, he/she is exposed to the risk of being eyed suspiciously from doctors. In other words, unlike persons with a common disease that can be relatively easily diagnosed and treated appropriately, persons suffering from ME/CFS are at a risk of being treated unfairly by doctors and medical institutions, and they are in a situation where they have no choice but to exert their own efforts.

4.4 Dependent-Patient Role Stage: Reversibility of Diagnosis, Unstable Patient Status

In the dependent-patient role stage, the rights of patient-management are usually delegated to the doctor and the prescribed treatment is accepted and followed. However, in case of ME/CFS where there is no fundamental treatment even after a definitive diagnosis, there are many cases in which patients contacted other medical institutions in search of better treatment or a hospital that is easier to visit. However, there are also cases wherein the diagnosis of ME/CFS has been reversed. For instance, Ms. H, who was looking for a more geographically accessible hospital was diagnosed with Idiopathic Chronic Fatigue (ICF) at a hospital. Although ICF satisfies part of the diagnostic criteria of CFS, it is a pathological condition different from CFS (Tajima and Kuratsune 2009). Despite being diagnosed as CFS, Ms. H was unexpectedly told that it was ICF. She stated, "I felt denied what I experienced until now. I was depressed for a

week.” Ms. H explained why she was very depressed as follows:

Ms. H: Well, I felt like I was back to square one (pointing at the words “psychiatric department” written on the field note; this “psychiatric department” is in the hospital where she was going before the definitive diagnosis). At that time (when I was told ICF), I felt I am being told about emotional and mental problems again.

Even though Ms. H was in the dependent-patient role stage with ME/CFS, she returned to the pre-diagnostic mental state as she was told that the diagnosis could be different. Later, another hospital supported the diagnosis of ME/CFS, and presently Ms. H is able to maintain a stable patient identity. However, it can be seen from Ms. H’s case that even after obtaining a definitive diagnosis, there is a fear that the presence of ME/CFS can be fundamentally denied, depending on the situation.

Incidentally, when the patients finally understand what is happening to their bodies after being diagnosed with ME/CFS, some of them take actions to strengthen their patient role by joining a patient association or by searching for available systems. This is inevitable for ME/CFS patients, where there is no fundamental treatment, as many critically ill patients lose their financial base, which makes it difficult for them to carry on with their social life. However, even in this stage, patients will find themselves in a predicament similar to that seen in the previous section because despite diagnosis and actually being in a helpless physical condition, the people around them neither regard it as a disease nor take it seriously. For instance, Ms. B said the following of her consultation with a public health nurse about the presence or absence of a usable system one year after the definitive diagnosis:

Ms. B: I consulted with a local public health nurse. However, I was told that there was no such system. Well, anyway, I was told that I cannot receive any services because [the disease] was not in the system. Then I had the nurse visiting me multiple times. At last I was told, “I can’t do anything, but I can come just to hear your complaints.” I was shocked a little by those words. I was trying to appeal but that was just heard as a complaint. I consulted with them many times..... The public health nurses were in the position that they could come only to hear complaints. During the talk, I was told that it didn’t seem like I needed a welfare service.

From this narrative, it may be seen that as far as public health nurses are concerned, the diagnosis and symptoms of ME/CFS are not seriously consideration. In the eyes of public health nurses, Ms. B’s condition, in which it was difficult to determine the presence/absence of symptoms by her appearance, it did not seem like an “illness” that must be cared for, even after multiple visits. Ms. B was seen as a person who just wanted someone to listen to her

complaints. Let us now consider a similar situation in the case of Mr. F, who even after being diagnosed was not considered “sick” by his family. Prior to the onset, Mr. F actively enjoyed camping and mountain climbing. However, after the onset, he was completely exhausted and his wife could not understand his condition. Although Mr. F tried to explain his illness, his wife denied the presence of ME/CFS. Although his wife had seen his slumped appearance every day, she would say, “It’s just a problem in your mind. Somehow, you just want to skip doing your daily chores. Don’t you?” In other words, it appeared to Mr. F’s wife that Mr. F was pretending to be ill to shirk his duties such as daily chores.

From the cases of Ms. B and Mr. F, it can be seen that, as the surrounding people would not recognize the “illness,” the needs deeply rooted in the patient’s body turn into an “excessive demand.” As the needs of ME/CFS patients whose symptoms cannot be visualized are manifested in their complaints, the surrounding people label such behavior as “selfishness” or “seeking an excuse.” The needs of a patient, which would normally be accepted without reservation in the case of a common disease, are exposed to the danger of invalidation in the case of ME/CFS, whose status as a disease has not necessarily been established.

4.5 Recovery and Rehabilitation Stage: Impossibility of Simultaneously Performing Patient Role and Normal Role

As recovery from ME/CFS is extremely difficult, returning to a normal role is rare. In this research, although two working people experienced this stage, they never abandoned their patient role as they never recovered from the disease. In other words, they were performing the patient role and the normal role simultaneously. However, that does not mean that they were able to work like healthy people. Although Ms. H, who was leading a social life while suffering from ME/CFS, conveyed to her superiors that she had ME/CFS; her colleagues did not know about it. Hence, to perform the normal role, Ms. H sometimes tried to overwork and became unable to move. She reported to have spoken out, “I want them to understand that I am ill,” thus showing how difficult it is to conceal the patient role and continue working.

On the other hand, Mr. F, who works in a workplace that understands ME/CFS, also feels frustrated that he is unable to force himself to work. Prior to onset, Mr. F was recognized by himself and others as a hard worker. Hence, his real intention was to work more if he could. However, even though he faces the dilemma of being unable to work the way he wants, Mr. F, who unlike Ms. H is in an environment where everyone supports him, can continue working without having to conceal his patient role. Certainly, even though the support system is substantial, there will be many situations where Mr. F will be forcing himself to do more. However, an environment that not only knows about ME/CFS but also understands and provides support becomes the basis for leading a social life without sacrificing the patient role.

5. Discussion

5.1 Complicating the Illness Behavior

In the previous section, we identified the illness behavior of people suffering from ME/CFS and the problems that arise from it stage by stage. It is clear that ME/CFS is not something that entails a smooth transition between stages as shown in the hypothesized acute disease five-stage model. In particular, the “contacting a medical institution” stage and the “dependent-patient role” stage are prolonged and/or complicated due to “doctor shopping,” conducted to seek a definitive diagnosis and a hospital with better conditions. In the illness behavior theory, it is said that if the patient does not accept the first diagnosis, the “contact medical institution” stage will be prolonged. However, persons suffering from ME/CFS do not blindly refuse the medical advice that is not related to ME/CFS. The background of the complications in the illness behavior of persons suffering from ME/CFS lies in their complaint being denied by medical professional and in being criticized inconsiderately, in addition to being shuffled through different departments due to the ignorance and negligence of medical professional. For instance, even Ms. B, who received a definitive diagnosis in a relatively short time, experienced being unable to receive a proper examination by medical professional.

Ms. B: I started seeing the doctor who my mother was consulting and waited to see what happens for a bit longer. When I told the doctor about my situation in X (month), he introduced me to another hospital. Well, I was introduced to the local university hospital. However, I did not get any medical examination done in particular. Then, they directed me to another doctor, but somehow, I was sent to an endocrinologist and diabetologist. I was sent there for the reason that it would be better to consult with another specialist, but I was told something like, “The more you measure your fever, the more it will go up” (laughs). They paid no attention. In no time, I was pushed into a psychosomatic department.

A case like Ms. B’s is by no means exceptional. As seen in the previous section, the hospital Ms. D was visiting, which was friendly until then, suddenly changed its attitude and became non-cooperative when Ms. D expressed her suspicion that it could be ME/CFS. Such an attitude of the hospital bewildered Ms. D, which was enough to force her to seek another hospital. In the case of ME/CFS, whose status as a disease has not been established, cases such as Ms. B’s and Ms. D’s probably represent the tip of the iceberg. In the background of the seemingly excessive treatment behavior called “doctor shopping” it is necessary to point out that, in addition to the delicate signs on the patient’s side of wanting to get rid of “inappropriate” labels like laziness and mental disorder, there are also problems on the medical professional side such as ignorance, suspicion, and lack of understanding of diseases that do not have biomarkers.

5.2 Impossibility of the Dependent-Patient Role Stage and Undertaking the Independent-Patient Role Stage

In addition to the lack of a smooth transition between the stages of illness behavior, difficulty in experiencing each stage stably is also a major discrepancy from the five-stage model. In particular, in the dependent-patient role stage, persons with ME/CFS do not gain a stable status as patients even after obtaining a definitive diagnosis. Hence, they find it difficult to carry out the patient's role of "trying hard to get better," even if they want to do so. Specifically, due to the dismissal of their diagnosis and not being regarded as a "disease" by people around them, the sufferers experienced a wavering situation of being a "patient."

However, in such a situation where it is hard to recognize ME/CFS through definitive diagnosis alone, the sufferers will not just stand idly by. With the cooperation of the people around them, such as family members and social workers, many people have assumed the role of being a patient by performing activities such as collecting information on the disease, joining patient associations, and appealing to the government and politicians for welfare services. In the dependent-patient role stage, persons with ME/CFS do not simply depend on the words of medical professional but also take necessary actions following their own intentions and judgments to live as patients. Due to such behavior, this stage could be called the independent-patient role stage. In this stage, people suffering from ME/CFS try to acquire the status of "patients" through various activities because, as seen in the previous section, ME/CFS, which cannot confer the dependent-patient role like acute diseases, is in a situation where it is hard to gain social recognition as an "illness" just by being granted medical legitimacy. People with ME/CFS whose status as a patient is unstable even after definitive diagnosis must become active patients and acquire legitimacy for their disease themselves⁸⁾.

6. Conclusion

In this paper, we analyzed the problems associated with the illness behavior of people suffering from ME/CFS with reference to the five-step model of illness behavior. It is clear that as people with ME/CFS are less likely to be considered "ill" even after a definitive diagnosis, leaving them in a situation similar to that before the definitive diagnosis, they face difficulties in accomplishing the patient role. Furthermore, it is also clear that while people with ME/CFS have difficulty in taking up the dependent-patient role, they prepare themselves for what should be called the "independent patient role" and acquire legitimacy for their illness through their own efforts. It can be thought that these could be clarified by examining the problems associated with illness behavior and their transformation processes, paying

8) As this paper is entirely based on the experiences of the members of the patient association, it is important to remember that not all ME/CFS patients will become "active patients."

attention to their deviation from the five-stage model.

Furthermore, when considering the independent-patient role stage, it should be borne in mind that patients do not act in pursuit of secondary gain. As ME/CFS is hardly considered an “disease” even after obtaining a definitive diagnosis, under the current situation where appropriate care is not forthcoming for the symptoms, it is presumed that the definitive diagnosis of ME/CFS is not effective enough for social approval of the illness.⁹⁾ Therefore, despite being in a condition where they are unable to eat or even move around their home, people with ME/CFS are forced to become active patients so that they will be treated fairly as patients and be permitted to perform their patient roles. Hence, it should be added that they do not seek too much sympathy or assistance from their milieu¹⁰⁾.

Finally, I would like to mention future study. In this paper, although we focused on ME/CFS, there is room to consider whether the same problems occur in the case of other types of MUS. To generalize the problems of people suffering from the disease group called MUS, which is hardly considered a “disease,” it is also necessary to focus on the illness behavior of people suffering from other types of MUS such as FM and IBS. If problems common to all of the MUS can be extracted and compared with the problems involved in common diseases, it will be possible to propose new models for discussions that have so far dealt with general diseases such as the illness behavior theory and the patient role theory.

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9) Currently in Japan, as the diagnostic criteria of CFS are being adopted instead of those of ME, most of the patients who obtain definitive diagnosis are diagnosed with CFS. Diagnosis as CFS does not determine social endorsement of the disease because the disease “CFS” and the patient’s actual condition are not socially recognized. Further, as seen in Note 4, it is possible that the disease name CFS leads to the misunderstanding that it is “not serious.”

10) In sociology of medicine, such attitudes and behaviors of patients have tended to be considered negatively as constituting a part of excessive medicalization. However, as seen in this paper, as ME/CFS patients have not been able to stabilize their status as patients even after obtaining a definitive diagnosis, they are in a situation where they are unable to receive the necessary care. In this case, it may be considered insufficient medicalization rather than excessive medicalization.

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